Pediatric Cochlear Implants: Medical Miracle or Cultural Genocide?

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Introduction

Hearing is a complex sense that is paramount to a child's cognitive, linguistic, and social development. In the United States, nearly 20 million people and 3 out of every 1,000 children are born deaf or hard-of-hearing every year. As of April 2009, 25,500 children in the United States have received cochlear implants (National Institute of Deafness and Communication Disorders, 2009). The cochlear implant is a surgically implanted device that bypasses the outer ear and is directly inserted into the cochlea. The implant electrically stimulates the auditory nerve fibers, which translate impulses into sound (Berg, Herb, & Hurst, 2005). This breakthrough technology was first approved for trial in 1985 and approved by the FDA for surgical implantation in children two years or older in 1990 (Berg et al., 2005). The invention of this device was viewed as a miracle by the medical community for the ability to cure the deaf. However, to the deaf community, the cochlear implant was a direct attack against deaf culture. With the use of cochlear implants, it is feared that the deaf way of life will disappear. Due to the success of implantation, the criteria have broadened to consider children as young as 18 months and at various testing centers, only 6 months (Berg et al., 2005). This puts parents in a unique position of deciding what is in the best interests of the deaf child. Pediatric nursing is likely to see an increase in patients undergoing cochlear implant surgery due to the rise in technology, and it is imperative for nurses to understand the implications, both physical and mental, of this controversial procedure.

This controversy has created an ethical dilemma between the deaf cultures ability to thrive, paternalism, and acting in the best interests of the child. The purpose of this paper is to discuss the implications of pediatric cochlear implantation.

Review of Literature

To understand the turmoil that underlies this heated controversy, it is important to look at deafness as a minority culture within the hearing world. A culture consists of members with a "shared history, social life and sense of identity" (Hyde and Power, 2000, p.118). The deaf community shares their own form of communication, American Sign Language, and a shared set of values centered on autonomy and independent living. The members of the deaf world believe that the absence of hearing is far less important than the ability to share a culture and language (Berg et al., 2005). Being deaf carries the same disadvantages as does any other minority group, including discrimination, a lower level of education, reduced life expectancy, and higher rates of unemployment (Levy, 2002). The increased use of cochlear implants means a decrease in the use of American Sign Language and the values of deaf life. This is a view that many people from the hearing community are unable to comprehend because many are taught that being deaf is the absence of a physical trait and considered a disability.

If deafness is a genuine culture, and not a disability, then allowing medical intervention to correct the problem may be viewed as unethical and could lead to the demise of the deaf world. The medical model views deafness as something that can be cured. This view contrasts with the social-cultural model, which sees a viable future as a deaf person (Hyde & Power, 2000). Members of the deaf culture believe that being deaf is a "good thing and would like to see more of it" (Lane & Grodin, 1997, p. 234). To those, being deaf is a way of life and not a disability. When defined as a disability, deafness is something that should be repaired, fixed, altered, or improved. By implanting young children with cochlear implants, society is sending the message that the child needs to be 'fixed' to be normal and live in today's world (Delost & Lashley, 2000). Levy (2002) states that trying to fix the deaf sends the wrong message that "we want no

more people of 'your kind', no more disabled people, no more Deaf people" (Levy, 2002, p. 142). Most deaf children are born to hearing parents. Cochlear implants allow a quick fix that makes it possible for the deaf child to participate in the hearing family and culture. The idea of a quick solution could lead hearing parents to unrealistic expectations of their child's social, development, and linguistic future (Berg et al., 2005).

Cochlear implants involve serious medical and surgical risks. The surgery involves drilling into the temporal bone and includes complications such as infection, damage to facial nerves, and increased risk of otitis media and meningitis. Children with cochlear implants are not able to participate in contact sports, play in pits of plastic balls, or slide down plastic slides due to the risk of injury and electrostatic discharge (Delost & Lashley, 2000; Okubo, Takahashi, & Kai, 2008). In a study following 300 pediatric cochlear implantations, conducted by Nottingham University Hospital, seven (7) experienced major complications and forty eight (48) resulted in minor complications. Research about the lasting effects of cochlear implants is still yet to be conducted (Okubo, Takahashi, & Kai, 2008).

Those who advocate for cochlear implants have a compelling argument about how living in a world of sound could benefit deaf children. Perceived benefits of implantation include auditory improvement and speech production (Okubo, Takahashi, & Kai, 2008). Oral speech alone leads many families toward cochlear implants because of the ability to interact with hearing society, respond to the environment, and reduce social stigma. The problem arises with the efficacy of cochlear implants. Effectiveness of the implant is variable and dependent on many things including non-modifiable factors such as IQ, socioeconomic status, gender, family size, and educational program (Berg et al., 2005). Implants do not guarantee the ability to hear and acquire spoken language. Lane's 1995 study of children born deaf and implanted at an early

age showed that the majority of implanted children were unable to follow instructions or answer any oral questions correctly on a test after 5 years of implantation (as cited in Lane and Grodin, 1997).

After surgical implantation, the child does not hear immediately. It can take anywhere from two weeks to two years before the child begins receiving auditory input (Delost & Lashley, 2000). Implantation is typically followed by extensive language therapy with speech pathologists, special teachers, and requires hours of commitment (Lane & Grodin, 1997). Cochlear implant surgery is not approved by the FDA under the age of 12-18 months and is then typically followed by an additional silent period where the device cannot be used (Berg et al, 2005). This time gap puts the child at a significant language delay compared to their hearing and deaf peers. By waiting to acquire a language, mastery often decreases and can lead to altered "intellectual, social and psychological development" (Lane & Grodin, 1997, p. 236).

The true issue that lies behind the implantation of children is the violation of autonomy. Advocates of the cochlear implant state that the most effective outcomes are achieved at the youngest age of implantation (Berg et al., 2005). However when young children are implanted, residual hearing is permanently destroyed, as are the possibilities of future technological applications (Berg et al., 2005). Parents must sign an informed consent for this complicated surgery stating they understand all benefits/risks associated. This decision, made for the child but not by the child, violates personal autonomy and determines the child's future.

The decision to implant a child can result in negative psychosocial effects. Although cochlear implantation might improve hearing or allow for the acquisition of spoken language, the child is still truly deaf. This places the child without a true identity in society. To the hearing world, they are abnormal, and to the deaf world, they are hearing (Okubo, Takahashi, & Kai,

2008). Implantation could be viewed as a paternalistic action, which enforces a particular way of life upon children (Berg et al., 2005). Parental surrogacy is approved for many medical instances in which the lives of children are threatened. However in the case of cochlear implants, being deaf is not life threatening. Deaf children are not in immediate danger. One should have the right to preserve one's body and determine personal identity, this is why deaf advocates argue that cochlear implantation should be withheld until a child is able to request and understand the full consequences of that decision. This prevents paternalistic actions that are made with intent to do what is in the best interest of the child (Berg et al., 2005).

Conclusion

The cochlear implant is a medical invention that is now the center of a swirling controversy. The cochlear implant was created to enlighten the deaf with the joy of hearing. It was not until after the FDA approval of this small device, did the medical community realize that many deaf are happy being deaf. Cochlear implants not only degrade the deaf and force a feeling of inadequacy, but they also undermine the deaf way of life. Due to increased effectiveness of early implantation, several ethical issues are now at the center of this debate. Arguments have emerged over parental surrogacy and trying to preserve the individual's right to autonomy. To prevent cochlear implant complications, negative psychosocial effects, delayed language acquisition and possible resentment toward a forced way of life, cochlear implants should only be allowed when one is old enough to request and understand the consequences of such action. With increasing technology, nursing is likely to see advances in cochlear implants and hearing aids in the future. By understanding what lies behind the decision to receive a cochlear implant, the nurse will be able to provide appropriate care to deaf families and children.

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